California's State Plan for Alzheimer's Disease: An Action Plan for 2011-2021

Status Report and Recommendation of Philanthropic Funding Priorities

Presented to the California Health and Human Services Agency
Alzheimer's and Related Disorders Advisory Committee
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Background:
In 2008, two important policy developments occurred: 1) the Legislature enacted and Governor Schwarzenegger signed SB 491 (Alquist) into law, authorizing development of California's first statewide report on Alzheimer's disease in more than two decades, and 2) The Rosalinde and Arthur Gilbert Foundation funded the UCSF produced Alzheimer's Disease Facts and Figures in California, publicizing alarming data on the doubling rate of Alzheimer's disease in the next generation.

In [insert year], under the leadership of the California Health and Human Services Agency's Alzheimer's Disease and Related Disorders Advisory Committee, and with generous philanthropic support from **Archstone Foundation**, **The California Endowment**, **The Rosalinde and Arthur Gilbert Foundation** and **The SCAN Foundation**, California embarked on a robust, year-long, public-private planning process unmatched by any other state. With guidance from the Alzheimer's Association, the State Plan Task Force – co-chaired by Sherrie Matza and Joshua Chodosh, MD, MPH, engaged more than 2,500 individuals in 15 communities spanning from Eureka to San Diego. Multiple outreach strategies were employed to ensure diverse representation including town hall meetings, small group discussions, educational forums, on-line surveys and key informant interviews. Of special note, California's plan actively involved 90 individuals in the early stages of Alzheimer's disease, seeking their firsthand input into the program needs and priorities of the target population.

Throughout 2009-2010, in both formal State Plan Task Force and informal community meetings, the statewide effort focused on three guiding principles:

1. *Promote **person-centered care** that is responsive to individual need.*
2. *Address the broad cultural, ethnic, racial, socio-economic and demographic **diversity** of California's population.*
3. ***Integrate the social and medical needs** of this and other aging populations living with multiple chronic diseases and disabling conditions.*

State Plan Task Force Process:
The Secretary of Health and Human Services named a statewide task force of 22 members who reflected the medical, social, research and family caregiving needs of all

Californians. The State Plan Task Force met in-person six times, with their work augmented by three task-specific committees, on which an additional 11 subject matter experts participated. In addition, the task force relied on technical experts for complicated subjects such as long-term care financing and end-of-life care. Quarterly updates were provided by the task force to the California Health and Human Services Agency's Alzheimer's Disease and Related Disorders Advisory Committee, chaired by Patrick Fox, MD of the University of California, San Francisco (UCSF).

Goals and Recommendations:
In December 2010, the task force produced its final report *"California's State Plan for Alzheimer's Disease: An Action Plan for 2011 – 2021,"* presenting their findings to then Secretary Kim Belshé as the Schwarzenegger Administration concluded and Governor Edmund G. Brown, Jr. prepared to take office. Below are the comprehensive goals and recommendations:

1. **Eliminate Stigma**
    a) Heighten public awareness through culturally appropriate public education campaigns.
    b) Ensure established clearinghouses have reliable information.
    c) Promote consumer access to established clearinghouses.
2. **Ensure Access to High Quality, Coordinated Care in the Setting of Choice**
    a) Develop a comprehensive, accessible network of medical care and long-term services and support from diagnosis through end-of-life.
    b) Advocate for accessible transportation systems.
    c) Address the affordability of services across the long-term care continuum.
3. **Establish a Comprehensive Approach to Support Family Caregivers**
    a) Acknowledge and invest in the informal, unpaid caregiver as a vital participant in care.
    b) Sustain and expand California's statewide caregiver support network.
4. **Develop an Alzheimer's Proficient, Culturally Competent Workforce**
    a) Build and expand workforce capacity and competency throughout the continuum of care.
    b) Improve dementia care capacity and competency of primary care providers.
5. **Advance Research**
    a) Sustain and expand existing research efforts.
    b) Increase participation in research.
6. **Create a Coordinated State Infrastructure that Enhances the Delivery of Care**
    a) Implement a statewide strategy to coordinate, integrate, deliver and monitor the continuum of care and services.
    b) Incorporate public health approaches to prepare for significant growth in Alzheimer's disease.
    c) Collect and use data to drive service development and delivery

Early Momentum:
While not officially responsible for the dissemination, management or implementation of the state plan, SB 491 (Alquist) did require the Health and Human Services Agency's

Alzheimer's Advisory Committee to "regularly review and update recommendations as needed." The committee was initially very receptive and enthused to oversee the document, but they quickly found that their quarterly meetings were no match for the far-reaching implementation strategies. They devoted the first year to organizing the content, assigning responsibility to various state departments, soliciting updates on activities, and strategizing on how best to tackle the multiple private sector/philanthropic ideas that were not within the purview of state government. The committee is to be commended for their foundational work and their commitment to periodically tracking progress, without a legislative mandate or commensurate budgetary support.

Early Challenges:
Of the more than 40 states with Alzheimer's disease plans, California's is by far the most comprehensive and progressive, yet its full potential has not yet been realized due to a variety of factors, chief among them the state and national recession of 2007-09. California's dire economic condition necessitated severe cuts to existing programs and services benefiting older adults and persons with disabilities, a temporary crisis situation that precluded the state from investing in new initiatives or funding state plan implementation strategies. Even private philanthropies were hurt by the recession, as evidenced by original or potential state plan funders curtailing funding as their respective foundation assets declined and funding needs expanded.

Secondary to the primary economic challenge facing the entire state, in hindsight the structure of the enabling legislation (SB 491 – Alquist) did not foster sustainable results. By loosely assigning responsibility to an all-volunteer advisory committee, the plan itself was not officially housed in state government with state personnel assigned responsibility *per se*. There was no state budget allocation or any continuing appropriation to fund implementation, nor were there private philanthropic dollars allocated for this purpose. And finally, , there was neither a mandate nor requirement to bring the state plan results or progress before any legislative committee, even if only for informational purposes. Ultimately, this has led to the state plan serving as an internal reference document rather than the public platform it was intended to serve as.

It has been said, with great dismay, that California's comprehensive and progressive state plan has "languished" and that sentiment – shared by many, is particularly relevant today as the 10-year plan approaches its mid-point in 2015.

New Progress:
While California struggled to rebound from the recession, and the state Alzheimer's disease plan languished as a result, several new key federal developments occurred:

The **Patient Protection and Affordable Care Act (ACA)** became law, with California responding with its own health insurance exchange and marketplace: Covered California. The triple aim goals of improving individual care, addressing population health and reducing costs apply to both public and private payors, as states embark on broad delivery system change. As a result of the ACA, California has expanded

individual and small business coverage through the exchange and enrolled more than a million new beneficiaries in Medicaid (Medi-Cal).

Congress passed and President Obama signed into law the **National Alzheimer's Project Act (NAPA)**. NAPA creates an important opportunity to build upon and leverage U.S. Department of Health and Human Services (HHS) programs and other federal efforts to help change the trajectory of Alzheimer's disease and related dementias. The law calls for a National Plan with input from a public-private Advisory Council on Alzheimer's Research, Care and Services. The Advisory Council will make recommendations to HHS for priority actions to expand, coordinate, and condense programs in order to improve the health outcomes of people with Alzheimer's disease and reduce the financial burden of these conditions on those with the disease, their families, and society.

The Centers for Disease Control and Prevention (CDC) developed the second in a series to advance cognitive health as a vital, integral component of public health: *The Healthy Brain Initiative: The Public Health Road Map for State and National Partnerships, 2013 – 2018*. The **Healthy Brain Initiative** addresses specific actions in four traditional domains of public health: monitor and evaluate, educate and empower the nation, develop policy and mobilize partnerships, and assure a competent workforce.

For the first time, the Centers for Disease Control and Prevention (CDC) approved two optional modules: 1) measuring caregiver burden, and 2) assessing cognitive status, clearing the way for each state to adopt each question on its annual **Behavioral Risk Factor Surveillance System (BRFSS)** survey. This is a valid instrument to determine the accurate size and scope of Alzheimer's disease as a public health concern.

Recommended Philanthropic Funding Opportunities:

#1: Coordinated Care Initiative Dementia Care Coordination: Invest strategically in California's Coordinated Care Initiative (CCI), including itsCal MediConnect demonstration project, by expanding the scope and reach of the U.S. HHS, Administration for Community Living – Alzheimer's Disease Supportive Services Program (ADSSP) grant to California. This grant achieves three goals of the state plan: 1) establishes and provides access to dementia care coordination within contracting health plans pursuant to 3-way contract language agreed to by CMS, the California Department of Health Care Services (DHCS) and participating health plans, 2) builds care manager, nurse and social worker competency, and 3) acknowledges and invests in unpaid care partners through assessment, follow-up and support services. (Addresses Alzheimer's Disease State Plan Goal areas #2, 3 and 4)

Possible funding partners:

> **The SCAN Foundation** is committed to the Coordinated Care Initiative's success and has two organizational strategies to integrate care and financing,

and to put individuals and their families at the center of care decisions. Further, SCAN's recently released national scorecard on long-term services and supports called attention to California's need for improvement in two related areas: support for family caregivers and care transitions.

The Rosalinde and Arthur Gilbert Foundation focuses on Alzheimer's disease with an emphasis on caregiver support.

Archstone Foundation subscribes to a responsive grantmaking program that includes caregiver support and professional education/training among other focus areas.

The Masonic Foundation of CA was not an original funder but has an Alzheimer's-directed endowment and is very interested in nurse leaders and nursing practice (~90% of dementia care managers/coordinators/specialists are RNs); there are two Masonic Homes in CA located in Reseda and Union City, both participating counties in the 8-county demonstration project; Masons are concerned with caregiver burden and support.

Health plans and their charitable foundations.

#2 Guidelines for Alzheimer's Disease for Physicians and Managed Care Plans: Update *California's Guidelines for Alzheimer's Disease Management* in partnership with the university-affiliated California Alzheimer's Disease Centers and disseminate widely to primary care physicians, physician groups and managed care plans. Since the Guidelines were last updated in 2008, significant changes in screening, detection and diagnosis have occurred with consensus evidence available now to support a change in post-diagnostic practice. This supports the goal of developing a culturally competent, Alzheimer's proficient workforce. (State Plan Goal area #4)

Possible funding partners:

Archstone Foundation subscribes to a responsive grantmaking program that includes caregiver support and professional education/training among other focus areas.

The Masonic Foundation of CA may be interested in improved screening, detection and diagnosis among its members and their families, as well as seeing more clinical and social support post diagnosis.

#3 Statewide Survey by Department of Public Health: Propel forward the Centers for Disease Control's (CDC) Healthy Brain Initiative by acting on the recommendation to implement the two recently approved optional caregiver and cognitive status modules on California's Department of Public Health annual Behavioral Risk Factor Surveillance System (BRFSS) survey that commences January 1, 2015. This data is critical to determine prevalence rates/trends in CA, supporting state plan goals re: supporting family caregivers, advancing research and building on state infrastructure. (State Plan Goal areas #3, 5 and 6)

Possible funding partners:

Archstone Foundation subscribes to a responsive grantmaking program that includes caregiver support and professional education/training among other focus areas.

The Rosalinde and Arthur Gilbert Foundation focuses on Alzheimer's disease with an emphasis on caregiver support. Their early support of the California data report produced the last reliable data on prevalence rates in 2008.

AARP Foundation is interested in supporting caregivers, and AARP in California has introduced legislation (AB 1744 – Brown) to establish a blue ribbon panel on caregiving.

Other Funding Needs/Possible Funding Partners:

With the state plan approaching its mid-point in 2015 (2011 – 2021), it is timely to reinvigorate the critical and still relevant findings in the original plan. Because the initial recommendations were not ranked or prioritized, the most expedient approach at this juncture is to recommend specific high-priority activities with corollary allies/funders (e.g. the three noted above or others), and embark on targeted outreach to initiate new momentum. Health and Human Services Secretary Diana Dooley's leadership and influence are key to advancing any element of the state plan. In addition to the funders noted above, other possibilities include:

The California Endowment was an original partner in the creation of California's State Plan. Since that time, their funding has focused on 10 geographic areas in California. However, TCE could play a vital role in convening original (SCAN, Gilbert, Archstone) and potential new funders (Masonic, CHCF, Wellness Foundation, etc.) as well as key stakeholders (CHHS, CADCs, Alzheimer's Association, etc.).

The California HealthCare Foundation has related funding and program areas but no history with this project.

The California Wellness Foundation is announcing a new strategic direction and funding priorities in October 2014.

The Gordon and Betty Moore Foundation is interested in nursing education and patient/family engagement in health care.

<u>Next Steps: A 15-Month Strategy: October 2014 – December 2015</u>

1. **Adopt the Recommended Philanthropic Funding Priorities**: (These are described in more detail on p.4-6.):
   #1: Coordinated Care Initiative Dementia Care Coordination
   #2 Guidelines for Alzheimer's Disease for Physicians and Managed Care Plans
   #3 Statewide Survey by Department of Public Health

2. **Health and Human Services Agency Support:** Recommend that the Alzheimer's Advisory Committee advise Secretary Dooley for she and the Health and Human Services Agency staff to take specific actions (e.g. place phone call(s), write letters

or emails of inquiry, convene a meeting, etc), in partnership with the Alzheimer's Association California Council, to secure philanthropic funding for these priority opportunities.

3. **Identify Committee Members for a Workgroup:** The target would also be to put in place a small workgroup to carry momentum into 2015. This group would include representation from the Health and Human Services Agency, the Alzheimer's Advisory Committee, state department(s), the Alzheimer's Association.

   This group, in close consultation with the Health and Human Services Agency and the full Alzheimer's Advisory committee, would develop a 2015 work plan for each priority area, to include stated goal, strategies/tactics, partner(s), funding, outreach/awareness, indicators of success, and other key measurements.

<u>In Closing</u>

Consistent with the implementing legislation, this proposal calls for a public-private response reflective of new changes in law and regulation (ACA, CCI, etc.). While the state plan may have languished, the incidence of Alzheimer's disease and related dementias has not. Prevalence rates and public costs continue to climb with or without a state plan; implementing key strategies within the existing plan can positively impact California and the nation.